

HUMAN SERVICES BOARD

INTRODUCTION

A hearing in the matter was held on December 12, 2007. Testimony was taken (by phone) from the petitioner, her primary treating physician for many years in Massachusetts before the petitioner moved to Vermont in February 2007, and from the petitioner's case manager at the regional area Council on Aging. Following that testimony, the hearing officer requested, and the parties agreed, that an updated medical assessment of the petitioner by a doctor in Vermont be obtained. This was not completed until June 5, 2008. The record was held open until July 31, 2008 for the parties' submissions of written arguments.

FINDINGS OF FACT

1. The petitioner's condition and medical history are set forth in the following report, dated June 5, 2008, from the consulting doctor in Vermont, and is essentially consistent with the other medical reports and testimony:

She is a 64 year old woman who carries a diagnosis of chronic fatigue syndrome and multiple chemical sensitivity. She initially got disability back in 1999 but her symptoms actually started approximately 25 years ago. She had some surgery and found that she couldn't function after the surgery. She had extremely slow recovery, mainly with cognitive changes that prevented her from doing her job. She lost her job and has never been steadily employed since then. She has tried multiple jobs and has had short periods of employment.

[Petitioner's] present symptoms include fatigue, dizziness and falling episodes, nausea and diarrhea and fibromyalgia-like pain throughout her body. She also neuropathy of her fingers and toes based on her history. Her medical condition is characterized by good and bad days and when she is in a bad spell she has terrible cognitive problems in that her brain seems to run slowly. She can't think straight. She gets lost driving in a car. She forgets simple things. In addition, during her bad spells her weakness causes her to drop things and she falls more. She has extended periods of diarrhea and her pain is much worse. She describes that these spells can last from one day up to four or five days in a row. They are completely unpredictable except when she has a known exposure to a substance that she is sensitive to. She is so ill on these bad days that she reports that she cannot get out of bed, except she does manage to get to the bathroom and back. She says she has had accidents during these times because the diarrhea is so severe. She has no strength or ability to clean up her accidents nor can she prepare herself meals, do any house cleaning. During these periods she cannot get out and do any shopping. She usually does not eat and she is totally

dependent on other people to help her get through until she starts feeling better again. She recently was placed at Park House because she had no place else to go but because this is an institutional setting she had no control over what she was exposed to and patients with multiple chemical sensitivity problems do not do well in these settings because of the myriad of chemicals that they get exposed to. Her records indicate the chemicals that she has had problems with and these are very typical of other people with this condition.

I am not surprised that she has not been able to stay at Park House. She is also in a quandary that she is so ill and borderline functioning that she has a hard time looking for housing, particularly as her housing needs are so complicated. Getting exposed to chemicals that are toxic for her while house hunting prolongs the process.

I have treated half a dozen patients with this problem over the years and [petitioner's] symptoms and life experience is completely compatible with those other patients. This is an invisible and poorly understood medical problem but nevertheless she was granted disability nine years ago, so the diagnosis has been well established.

I think the major issue at this time is that [petitioner] is not functionally capable of performing activities of daily living all the time. Some days she is but other days she is totally incapable of caring for herself. On these days she should not be left alone.

I am convinced based on my evaluation of her and my review of her medical records that she is truly disabled by her chemical sensitivities and chronic fatigue, and that when she is in a flare of her symptoms she is ill enough to require additional help in the home. If she were required to go to the hospital or ER during these spells, her symptoms would likely only worsen.

2. The record includes two earlier reports from the petitioner's treating physician in Massachusetts. The more

recent report, dated July 20, 2007 (which is essentially a reiteration of an earlier report dated April 27, 2007)

provides as follows:

[Petitioner] is requesting that a care attendant assist her with daily activities. Her applications have been declined and I am writing in support of her receiving attendant services.

I have been working with [petitioner] from May, 1999 until February, 2007. She has a diagnosis of chronic fatigue, heavy metal toxicity, chemical sensitivity syndrome (CSS), depression, weak adrenal function, malnutrition, and peripheral neuropathy.

When [petitioner] suffers from an exacerbation of her CCS, she is debilitated. [Petitioner's] CSS has the potential for exacerbation every day due to a multitude of common chemicals that may trigger exacerbation, including extremely low doses of perfumes, detergent, lotions, vehicle exhaust, gasoline, fumes from construction work, cleaning agents, carpet fumes, pesticides, and solvents. Each exacerbation can last a day or more.

In addition to CCS, [petitioner] suffers from chronic fatigue and weak adrenal function. These disorders are continuous and also debilitate [petitioner] for days or weeks at a time. [Petitioner's] symptoms may be exacerbated by either exertion or stress.

Because both pervasive environmental factors as well as stress or exertion can trigger an exacerbation, normal, daily activities are debilitating for [petitioner].

Without assistance for daily activities, [petitioner] would suffer from exacerbation seven days a week. As a result, I strongly recommend that [petitioner] have a care attendant to assist her with her daily activities and help her maintain her independent lifestyle.

3. The above report is consistent with this doctor's subsequent testimony at the hearing on December 12, 2007.

4. As noted above, the petitioner's case manager at the area council on Agency also testified in the petitioner's behalf. Her testimony was consistent with the following report she had submitted, dated May 15, 2007:

Pursuant to my phone message left today, enclosed please find a revised and updated ASP application for [petitioner] of Rochester, including a letter from her physician. Her initial application did not accurately reflect her need for ADL assistance.

Among other conditions listed, [petitioner] has Multiple Chemical Sensitivity, which triggers a syndrome of allergic reactions that render the client virtually helpless during times of exacerbation (see attached physician's letter). [Petitioner] suffers exacerbation at least 3 times weekly. During these periods she requires assistance with the following ADLs: Toileting, Transferring, Ambulation, Dressing, in addition to her chronic need for Bathing and Meal Preparation.

Because [petitioner's] condition is triggered by numerous environmental substances, it is critical that a caregiver is hired who is willing to change their use of personal products, including laundry and personal hygiene, and wear client-directed clothing. VNA PCA staffing is frequently limited in the remote area; when it is available it is very difficult for the VNA to provide PCAs who will comply with the needs of a client with this condition.

ASP will allow [petitioner] to hire her own caregiver. She is competent to hire and train someone to provide her care. Therefore, I strongly recommend that she be found eligible for ASP PDAC. Thank you for your reconsideration of this matter.

5. Although the Department represented that it suspects the petitioner's complaints are being exaggerated, it

presented no medical evidence contradicting any of the above assessments.

6. Based on the above medical evidence it is found that the petitioner has episodes of near-total physical dysfunction during which she requires direct assistance with virtually all aspects of personal care and activities of daily living as described above by her case manager. However, on "good days" the petitioner is essentially able to function without any assistance. The frequency and duration of her episodes of dysfunction vary, and are largely unpredictable, although they are more likely to occur following periods of exertion, stress, or exposure to environmental irritants.

7. Other than her own self reporting, there are no objective findings or observations as to the frequency, duration and severity of the petitioner's episodes of dysfunction. As noted above, her doctors and caregivers appear to credit her reports that these happen several times a week. It is clear, however, that since she moved to Vermont the petitioner has been unable to secure a suitable and stable placement or residence. From the evidence in this matter, it would be difficult to quantify the petitioner's prospective need for assistance without a long-term

assessment and observation of her in a suitable and stable home environment. However, the evidence is clear that her need for such service will be frequent and ongoing.

8. At the last status conference held in this matter the petitioner represented that her daughter is willing to live with her and provide needed care for her whenever it is necessary. However, the petitioner stated she has not yet located a place to live that is suitable for her because of her environmental sensitivities.

ORDER

The Department's decision that the petitioner is ineligible for attendant care services is reversed, and the matter is remanded to the Department to determine the amount and delivery method of such services based on the petitioner's medical needs.

REASONS

33 V.S.A. § 6321 includes the following in the definition of Attendant care services:

(a) As used in this section,

(1) "Attendant care services" means one of more of the following types of care or service provided for compensation: assistance with personal care including dressing, bathing, shaving and grooming, and assistance with eating, meal preparation and ambulation.

Recipients of attendant care services shall have the opportunity to hire, train and terminate the employment of attendants as necessary, establish work schedules, manage the services and oversee payments of attendants and recordkeeping.

. . .

(3) "Personal services" mean attendant care services provided to an elderly or disabled Medicaid eligible individual in his or her home, which are necessary to avoid institutionalization.

(4) "Participant-directed attendant care" means attendant care services for a permanently, severely disabled individual who requires services in at least two activities of daily living in order to live independently.

. . .

(d) The commissioner shall adopt rules to implement the provisions of this section including eligibility criteria for the programs, criteria for determining service needs, rules relating to control and oversight of services by beneficiaries of a program and procedures for handling and maintaining confidential information. . .

Under the Department's regulations for "personal services" an individual must need physical assistance with at least one activity of daily living or meal preparation. For "participant-directed attendant care", the individual must need physical assistance with at least two activities of daily living. See Attendant Services Program Regulations 105(b). Contrary to the Department's determination, the above evidence is clear that the petitioner's condition is

permanent and not "reversible". Her dysfunctional episodes may be ameliorated, but will not disappear, if she can live in a "clean environment", even assuming such an environment is either possible or available. Thus, this aspect of the Department's decision can be reversed as simply contrary to the evidence.

However, the Department's position is also based on its interpretation of the regulations that the need for assistance with activities of daily living must be constant, not intermittent. The Department reads the regulations as limiting eligibility to those who require *daily* assistance with "activities of *daily* living", even though such a requirement is, admittedly, not specified in the regulations.

The Department correctly argues the interpretation of statutes and regulations by the administrative body responsible for their execution is controlling absent compelling indication of error. See Mountain Cable Co. v. Department of Taxes, 168 Vt. 454, 458 (1998). Indeed, the above statute is clear that the legislature intended to vest considerable discretion in the Department to define eligibility and criteria for service needs. In a past case involving other provisions of this same program the Board held that "assistance with personal care" need not include

individuals who required only *verbal* cueing and supervision, as opposed to "hands-on" *physical* care. Fair Hearing No. 16,168. However, this case is different.

In 33 V.S.A. § 6301 the legislature declared the "policy" behind its creation of the attendant care services program was "to ensure that all residents in every town within the state have access to comprehensive, medically necessary home health services . . . and to ensure that such services are delivered in an efficient and cost-effective manner". In this case there is no question that the service sought by the petitioner is "medically necessary" and that it is the same *type* of service provided to many other participants in the program. Nothing in the statute or the regulations indicates that an individual is, or should be, *automatically* disqualified from *eligibility* solely due to an intermittent, as opposed to daily, need for the service.

There may well be an issue in this case as to whether it is feasible, or even possible, to *deliver* services to the petitioner in a manner that will benefit her, and not waste resources on scheduling services when they are not needed. Certainly, however, there is no evidence at this time that the provision of services to an individual in the petitioner's circumstances is not feasible. Absent a clear

provision in the regulations, the Department cannot short circuit such a feasibility determination simply by declaring that the petitioner is ineligible for them. Inasmuch as the petitioner has clearly established a medical need for the type of service routinely provided to others in the program, the matter is remanded to the Department to determine the feasibility of delivering them to the petitioner in light of her individual needs. The petitioner shall have the right to further appeal if she is dissatisfied with the Department's determination in this regard.

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